

# Newborn Screening Update

Michigan Newborn  
Screening Program

Summer 2008

Volume 7 Issue 1



## Announcements....

The newborn screening follow-up program's new coordinator is Carole Flevaris, Ph.D. Carole has a multi-discipline background in public health, medical research and education, project management, rehabilitation, mental health and disabilities. Carole was an associate clinical instructor at a New England School of Medicine and has worked in several hospitals both in Michigan and New England. Carole looks forward to finding creative ways to work with each NBS hospital coordinator to assure stellar quality assurance in Michigan's newborn screening follow-up program.

## Newborn Screening Program Adds Saturday Testing

The Newborn Screening (NBS) laboratory began Saturday testing on June 21, 2008. These and other expanded services were required as part of recommendations by the MDCH Newborn Screening Quality Assurance Advisory Committee that went into effect March 2007. (Note: Senate Bill 794 amended the 1978 Public Act 368 by adding sections 5430 and 5432).

Initially the disorders that will be tested for are Congenital Adrenal Hyperplasia (CAH), Galactosemia (GALT) and those metabolic disorders diagnosed via Tandem Mass Spectrometry (Amino Acids, Fatty Acid Oxidation and Organic Acids). Other disorders will be added at a later date (timeline to be determined).

Please see page 7 to view complete announcement letter.

## Inside this issue:

Announcements	1
Saturday Testing	1
NBS Updates / Reminders	2
Updates Other Resources	3
Quality Assurance	4
Early Letter	5
Military Time Chart	6
Saturday testing letter	7
Screening card changes	8-10
Questionnaire	11

## Contacts

NBS Follow-up Manager  
William Young, PhD  
(517) 335-8938

NBS Follow-up Coordinator  
Carole Flevaris, Ph.D.  
(517) 335-8959

NBS Follow-up Educator  
Vacant Position

NBS Laboratory Manager  
Harry Hawkins  
(517) 335-8095

NBS Accountant  
Valerie Klasko  
(517) 241-5583

## **A. Updates - Newborn Screening Follow-up**

### **Newborn Screening Follow-up Program Coordinators Regional Meetings:**

NBS Follow-up will resume the follow-up education and coordination activities by having NBS Regional Coordinator Meetings across the State of Michigan. The meetings will provide valuable information and tools for NBS Coordinators. The first NBS Regional Coordinator's Meeting will be held in Lansing, at Sparrow Hospital on September 24, 2008. NBS Coordinators will be notified individually regarding attendance at the regional meetings in the future. If you have questions please call William Young, 517-335-8938.

### **Newborn Screening Follow-up Program Family Recognition Day:**

The Newborn Screening Follow-up Program at the Michigan Department of Community Health (MDCH) assures that all newborns are screened for 49 rare but treatable disorders and that all infants with positive tests receive confirmatory diagnosis and treatment. The Newborn Screening Follow-up Program strives to provide education and support to families touched by these disorders.

We recognize the importance and expertise of parents or individuals in managing a particular disorder. Because of this we are launching a **Parent and Family Network** initiative to provide education and increase parent involvement with the NBS program. The kick-off event, **Family Recognition Day**, is planned for Saturday, September 6, 2008, in Lansing, MI, at the Impression 5 Science Center, a hands-on family oriented museum.

### **Newborn Screening Card and Brochure Ordering:**

For ordering purposes the office that handles newborn screening cards and brochures will be closed on these upcoming state holidays: November 4, 11, 27, 28 and December 24, 25, 31. Contact person for newborn screening card / brochure ordering is NBS Accountant Valerie Klasko at (517) 241-5583.

### **Newborn Screening Price Card Increase:**

There will be a price increase effective October 1, 2008 for the newborn screening cards. Official notification will be going out to hospital administrators in the near future. As soon as this occurs the notification will be updated on our website under: **NBS card fee adjustment effective October 1<sup>st</sup>**. (Currently the letter from last fiscal year, dated August 20, 2007, is posted).

## **B. Reminders Newborn Screening Follow-up**

### **Parental Refusal Forms:**

If a parent should refuse the newborn screening, please fax a copy of the signed Parental Refusal Form your institution uses for our records to 517-335-9419. We often find out about missed cases if there is no match to a birth certificate or from Newborn Hearing when they receive a hearing slip but find no matching blood specimen in the database. If we had the refusal forms on file we would know not to contact your institution about getting a family in for the missed newborn screening blood test.

### **Returning the blue initial NBS specimen card for credit:**

Please include the completed NBS Card Replacement form with the top copy of the blue initial NBS specimen card when requesting credit. Please send both to the address noted on the form. The forms can be found on our website at: [Newborn Screening card replacement form](#)

## C. Updates - Other Resources

### **MDCH Birth Defects Prevention and Intervention Program Resources available for Michigan Families and Professionals,**

*Joan Ehrhardt, Program Coordinator and Nancy Deising, Care Coordination Specialist*



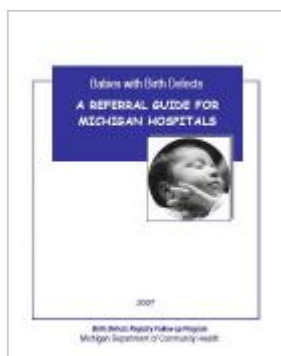
#### **1. Birth Defects Resource Kit**

Each kit contains more than 100 pieces of information from Michigan programs that support babies and young children such as Children's Special Health Care Services (CSHCS), Newborn Screening (NBS), Early Hearing Detection and Intervention (EHDI) and *Early On*® Michigan. Included are new resources designed especially for families and providers with input from community reviewers. The electronic version can be found on-line at: [www.michigan.gov/genomics](http://www.michigan.gov/genomics) and click on [Birth Defects and Genetic Conditions: Resources for Michigan Families and Professionals \( Toolkit\)](#) an [order form is available by clicking here](#) ([http://www.michigan.gov/documents/mdch/TK\\_order\\_form\\_1\\_244514\\_7.pdf](http://www.michigan.gov/documents/mdch/TK_order_form_1_244514_7.pdf))



#### **2. Special Care for Special Kids**

A guide for Michigan families, follows the Medical Home theme to support the need for accessible, family centered, coordinated, compassionate, and culturally effective care. The manual includes a section to help families keep track of information with sample forms to keep everything in one place. An electronic version is available at [www.michigan.gov/genomics](http://www.michigan.gov/genomics) and click on [Special Care for Special Kids: Guide for Michigan Families](#)



#### **3. Hospital Referral Guide**

For healthcare providers, summarizes Best Practices in referral to community resources when preparing for discharge of an infant with special care needs.

Please contact [mdch-newbornscreening@michigan.gov](mailto:mdch-newbornscreening@michigan.gov) to obtain any of the 3 resources listed above.

### **Birth Defects Prevention & Intervention Update**

Our nation's health care plan "Healthy Children 2010" recommended providing service systems for children with special health care needs. Within MDCH the development of the "Medical Home System" for children and youth with special needs involves numerous stake holders. The Birth Defects Program is partnering with Children's Special Health Care Services in this project. The American Academy of Pediatrics (AAP) recommends that the medical care of infants, children and youth should be accessible, continuous, comprehensive, family-centered, compassionate and culturally effective. According to AAP these characteristics define the "medical home system" concept.

## **D. NBS Quality Assurance**

### **EARLY Specimens:**

Just a reminder on Early specimens, those drawn at < 24 hours. At the bottom of the Early letter notice there is an area to CORRECT Birth Date, Time and Collection Date and Time information if this was filled out incorrectly on the specimen card submitted (**please see page 5 for example**). The majority of the time these corrections save the baby from being poked again unnecessarily. Please do not send detailed pages from the medical record with this information.

### **Importance of Filling Out Newborn Screening Cards Correctly:**

We ask that you please remind staff of the importance of filling out the newborn screening card completely and accurately. Incomplete or incorrect data entry, not using military time (see page 6) and entering data in the wrong fields on the specimen card are costly errors. Double check Birth Date/Time, Specimen Date/Collection Time, PHYSICIAN contact information and all required information to avoid time consuming errors that could delay reporting out a positive result.

Please refer to our website [www.michigan.gov/newbornscreening](http://www.michigan.gov/newbornscreening) for these helpful tools your staff can review: [Instructions for completing the Newborn Screening card](#) , [Newborn Screening Specimen Collection Presentation](#), [Newborn Screening Program Presentation](#)

### **Improved Turn Around Time with Courier Service, Saturday Testing and Faxes:**

The Newborn Screening Program has arranged for sample overnight delivery with both Quest Diagnostics and United Parcel Service (UPS). There have been noticeable improvements in the time it takes for NBS specimens to reach the MDCH Laboratory with courier services. The new NBS Saturday testing has significantly contributed to an even faster turn around time.

More than 93% of the babies are born in hospitals where arrangements have been made for overnight delivery with Quest Diagnostics or UPS . Please contact Carole Flevaris, Ph.D, Newborn Screening Follow-up Program Coordinator, with any questions about the courier delivery of NBS specimens and the coordination of NBS specimen delivery arrangements at your hospital. The parameters of turn around time are closely monitored in addressing quality assurance for prompt delivery of NBS specimens.

The State laboratory has been faxing newborn screening results to hospitals since January 2007 and is adding hospitals to the list of fax recipients. The fax option, for sending hospital reports, has replaced U.S. postal service mail delivery by fifty percent. Please contact Harry Hawkins, Newborn Screening Laboratory Manager at (517) 335-8095 if your hospital is interested in improving NBS turn around time for quality assurance purposes.



## Newborn Screening Program

201 Townsend CV4  
PO Box 30195  
Lansing, MI 48909

Phone: (517) 335-9205 Fax: (517) 335-9419  
Email: [mdch-newbornscreening@michigan.gov](mailto:mdch-newbornscreening@michigan.gov)  
Website: [www.mi.gov/newbornscreening](http://www.mi.gov/newbornscreening)

FACSIMILE TRANSMISSION ONLY

July 31, 2008

### EARLY SPECIMEN\* NEEDS PHYSICIAN REVIEW

Dear Doctor,

The newborn screening specimen obtained from this infant identified on the newborn screening card as your patient, was collected when the infant was less than 24 hours of age. This causes some of the test results to be inconclusive.

Baby:	Accession #:	Kit Number:
Birth Date:	Specimen Type:	Medical Record:
Collection Date:	Gender:	Gestation: wks
Collection Age:	Weight: grams	NICU:
Birth Order:	TPN:	
Birth Facility:		
Mother Name:		Phone:

Physician:	Phone:	Fax:
Submitter:		
Phone:	Fax:	

If the infant is <b>NOT</b> in the NICU / SCN	If the infant <b>IS</b> in the NICU / SCN and birth weight $\Rightarrow$ 1800gms	If the infant <b>IS</b> in the NICU / SCN and birth weight <1800gms
Call the parents and inform them of the early specimen.  A second newborn screen should be obtained on a pink repeat specimen card. The repeat newborn screen can be collected at the delivering hospital or nearest outpatient laboratory and should be forwarded to the Newborn Screening Laboratory ASAP.	If on TPN and/or Transfusions repeat newborn screen >72 hours after TPN and/or Transfusions discontinued.  If not on TPN and/or Transfusions repeat newborn screen ASAP.	Follow NICU protocol for obtaining repeat specimens at 14 and 30 days of age (or upon discharge).  If the infant is positive for any disorder please follow instructions as directed on the positive report.  If the infant receives continuous transfusion and/or TPN during the first 30 days, a repeat specimen should be obtained 72 hours after discontinuing transfusion and/or TPN and at 90 days post transfusion.  Alternatively, if there is a 72-hour window of opportunity during the first 30 days that the infant is not being transfused or receiving TPN, the post-72 hour repeat specimen should be obtained. This specimen would be in place of the 14 or 30-day specimen whichever is closer. The 14-day post transfusion specimen would still be required.

**\*Note: If your records indicate this specimen was collected at  $\Rightarrow$  24 hours please provide the following information and fax back to 517-335-9773 so that we may correct our records on this infant.**

Birth Date: \_\_\_\_\_ Birth Time: \_\_\_\_\_ Collection Date: \_\_\_\_\_ Collection Time: \_\_\_\_\_  
(Military) (Military)

CONFIDENTIAL

The information contained in this fax/print-out from the Michigan Department of Community Health, Newborn Screening Program is confidential in nature. It is for the sole use of the subscriber named on the report(s). If you are not the intended recipient, you are hereby notified that any disclosure, distribution, copying or the taking of any action in regard to the contents of this report is strictly prohibited. If you have received this report(s) in error, please telephone us immediately at (517) 335-9205 so that corrective action and destruction or return of the document(s) can be arranged.  
DCH-1272 (07/05) (W)

# Military Time

Military time is a concise method of expressing time used by the military, law enforcement, hospitals, and other entities. Military time uses a 24-hour time scale that makes the use of a.m. or p.m. unnecessary. Midnight corresponds to 0000, 1 p.m. corresponds to 1300, and so on.

The following table provides a convenient way to convert between military time and regular time.

Regular Time	Military Time	Regular Time	Military Time
Midnight	0000	Noon	1200
1:00 a.m.	0100	1:00 p.m.	1300
2:00 a.m.	0200	2:00 p.m.	1400
3:00 a.m.	0300	3:00 p.m.	1500
4:00 a.m.	0400	4:00 p.m.	1600
5:00 a.m.	0500	5:00 p.m.	1700
6:00 a.m.	0600	6:00 p.m.	1800
7:00 a.m.	0700	7:00 p.m.	1900
8:00 a.m.	0800	8:00 p.m.	2000
9:00 a.m.	0900	9:00 p.m.	2100
10:00 a.m.	1000	10:00 p.m.	2200
11:00 a.m.	1100	11:00 p.m.	2300





STATE OF MICHIGAN

DEPARTMENT OF COMMUNITY HEALTH  
LANSING

JENNIFER M. GRANHOLM  
GOVERNOR

JANET OLSZEWSKI  
DIRECTOR

June 2008

**Newborn Screening Program Adds Saturday Testing**  
**Start Date : June 21, 2008**

Dear Practitioner:

We would like to inform you that the Newborn Screening (NBS) laboratory will begin Saturday testing on June 21, 2008.

These and other expanded services were required as part of recommendations by the MDCH Newborn Screening Quality Assurance committee that went into effect March 2007. (Note: Senate Bill 794 amended the 1978 Public Act 368 by adding sections 5430 and 5432).

Initially the disorders that will be tested for are Congenital Adrenal Hyperplasia (CAH), Galactosemia (GALT) and those metabolic disorders diagnosed via Mass Spectrometry (Amino Acids, Fatty Acid Oxidation and Organic Acids). Other disorders will be added at a later date (timeline to be determined).

Any positive results (Strong or Borderline) will be reported out on Saturday. For Strong positives you will also be contacted by the medical management centers designated by the Michigan Department of Community Health and thus involved with the disorders mentioned above. These centers are: Endocrine Follow-up Program at University of Michigan for CAH and Children's Hospital of Michigan Metabolic Clinic (CHMMC) for GALT and the disorders diagnosed via Mass Spectrometry. As some of the disorders will need immediate follow-up, it is important that your voice mail instructions are clear as to how the medical management center can locate the responsible primary care provider or on-call physician in your practice on the weekend.

As during the week, the positive reports will be faxed to the physician's office recorded on the newborn screening card. We ask that your fax machines be left on over the weekend. Two attempts will be made to fax the reports and if they should not go through they will be held until Monday morning and re-faxed at that time.

If you have any questions or concerns, please do not hesitate to contact us at (517) 335-9205 or by e-mail at [mdch-newbornscreening@michigan.gov](mailto:mdch-newbornscreening@michigan.gov)

Sincerely,

William Young, PhD  
Manager, Newborn Screening Follow Up Program

DCH-1272 (07/05) (W)

201 TOWNSEND CV4 • P.O. BOX 30195 • LANSING, MICHIGAN 48909  
[www.michigan.gov](http://www.michigan.gov)



STATE OF MICHIGAN

DEPARTMENT OF COMMUNITY HEALTH  
LANSING

JENNIFER M. GRANHOLM  
GOVERNOR

JANET OLSZEWSKI  
DIRECTOR

To: Michigan Birthing Hospital Coordinators

From: State Newborn Screening

Re: Changes in the First and Repeat newborn screening cards

New/changed fields on **First** cards are:  
NICU / SPECIAL CARE?

New/changed fields on **Repeat** cards are:  
NICU / SPECIAL CARE?  
INFANT'S AGE (hrs) - **this field has now been deleted**  
INFANT'S BIRTH WEIGHT (gms) - **this field has now been deleted**

**On both the First and Repeat cards for**

1. NICU / SPECIAL CARE?

If baby is not in NICU or Special Care unit please mark **NO**. If baby is in NICU please fill in the **NICU oval**. If baby is in Special Care unit please fill in the **SP CARE oval**

**On the Repeat cards**

1. The following fields have been deleted:  
INFANT'S AGE (hrs)  
INFANT'S BIRTH WEIGHT (gms)



BABY

MOTHER

PHYSICIAN

SUBMITTER

BIRTH HOSPITAL  
 (if different from submitter)

LOT W071  
 6803708

Use By 2011-04

LAST NAME FIRST NAME GENDER ☐ MALE ☐ FEMALE

BIRTH DATE BIRTH TIME (Military) BIRTH WT. (gms) WKS GESTATION MULTIPLE BIRTH → SINGLE BIRTH BIRTH ORDER ANTIBIOTICS?

SPECIMEN DATE COLLECTION TIME (Military) Collected By: (Initials) NICU/ SPECIAL CARE? ANY RBC TRANSFUSION? YES DATE → NO SP CARE YES DATE →

MEDICAL RECORD # ANY TPN FEEDING? YES NO HISPANIC WHITE AMERICAN INDIAN ARAB DESCENT

NON-HISPANIC BLACK ASIAN/PACIFIC ISLAND. MULTI-RACIAL

LAST NAME FIRST NAME MOMBABY STEROID TX? NO YES

ADDRESS PHONE

CITY STATE ZIP SOCIAL SECURITY NUMBER

MEDICAL RECORD # BIRTH DATE HEPATITIS B SURFACE ANTIGEN (HBsAg) TEST DATE RESULT POSITIVE NEGATIVE

LAST NAME FIRST NAME

PHONE FAX

SUBMITTER NAME HOSPITAL CODE (if applicable) 00

ADDRESS PHONE

CITY STATE ZIP

MDCH  
 use only

MDCH USE ONLY

MI Dept. of Comm. Hlth.  
 By Authority of Act 568  
 P.A. MCLA 333.5431



Newborn Screening - Michigan Department of Community Health  
Bureau of Laboratories P.O. Box 30689 3350 N. MLK Jr. Blvd. Lansing MI 48909  
DCH-1154 04/08

REF 10534648 Rev.1

Print Firmly with Black Pen

DON'T USE RED INK

BABY		MOTHER		PHYSICIAN		SUBMITTER	
LAST NAME	FIRST NAME	LAST NAME	FIRST NAME	LAST NAME	FIRST NAME	LAST NAME	FIRST NAME
BIRTH DATE	BIRTH DATE	ADDRESS	PHONE	PHONE	FAX	ADDRESS	PHONE
SPECIMEN DATE	SPECIMEN DATE	CITY	STATE	ZIP	BIRTH DATE	CITY	STATE
MEDICAL RECORD #	MEDICAL RECORD #	ANY TPN FEEDING?	YES	NO	ANY RBC TRANSFUSION?	YES	NO
COLLECTION TIME (Military)	COLLECTED BY: (initials)	NICU SPECIAL CARE?	NICU	SP CARE	NICU	SP CARE	SP CARE
CURRENT WT. (gms)	CURRENT WT. (gms)	ANY RBC TRANSFUSION?	YES	NO	ANY RBC TRANSFUSION?	YES	NO
GENDER		GENDER		GENDER		GENDER	
BIRTH ORDER		BIRTH ORDER		BIRTH ORDER		BIRTH ORDER	
ANTIBIOTICS?		ANTIBIOTICS?		ANTIBIOTICS?		ANTIBIOTICS?	
ARAB DESCENT		ARAB DESCENT		ARAB DESCENT		ARAB DESCENT	
BLACK		BLACK		BLACK		BLACK	
ASIAN/PACIFIC ISLAND.		ASIAN/PACIFIC ISLAND.		ASIAN/PACIFIC ISLAND.		ASIAN/PACIFIC ISLAND.	
MULTI-RACIAL		MULTI-RACIAL		MULTI-RACIAL		MULTI-RACIAL	
HISPANIC		HISPANIC		HISPANIC		HISPANIC	
NON-HISPANIC		NON-HISPANIC		NON-HISPANIC		NON-HISPANIC	
BABY STERIOD TX?		BABY STERIOD TX?		BABY STERIOD TX?		BABY STERIOD TX?	
YES		YES		YES		YES	
NO		NO		NO		NO	
HOSPITAL CODE (if applicable)		HOSPITAL CODE (if applicable)		HOSPITAL CODE (if applicable)		HOSPITAL CODE (if applicable)	
00		00		00		00	
MDCH use only		MDCH use only		MDCH use only		MDCH use only	
W071		W071		W071		W071	
6803808		6803808		6803808		6803808	
Use By 2011-04		Use By 2011-04		Use By 2011-04		Use By 2011-04	

MI Dept. of Comm. Hlth.  
By Authority of Act 568  
P.A. MCLA 333.5431

MDCH USE ONLY

REPEAT SAMPLE

*We invite you to share positive experiences, suggestions and other NBS highlights in our newborn screening newsletter.*

*Please contact Carole Flevaris, Ph.D. at 517-335-8959*

Michigan Newborn  
Screening Program

201 Townsend Street  
Lansing, MI 48319

Phone: 517-335-9205  
Fax: 517-335-9419  
Email:mdch-newbornscreening@Michigan.gov

Please complete the questionnaire below so that we may update our records to serve you best. Fax to 517-335-9419

---

**Name**

**Title**

---

**Hospital or Institution**

---

**Address**

---

**Email**

---

**Phone**

**Fax**

**I prefer to receive a hardcopy of the NBS Newsletter**\_\_\_\_\_

**I prefer to receive e-mail copy only**\_\_\_\_\_

**NBS Screening & Follow-up topics that I would like to learn more about are:**

**1**\_\_\_\_\_

**2**\_\_\_\_\_

**3**\_\_\_\_\_

**4**\_\_\_\_\_